

The University of Mississippi Undergraduate Research Journal

Volume 2

Article 6

4-1-2017

The Early Adulthood Experience of Having a Sibling with a Developmental Disability

Carole Frances Jennings

Follow this and additional works at: <https://egrove.olemiss.edu/umurjournal>

Recommended Citation

Jennings, Carole Frances (2017) "The Early Adulthood Experience of Having a Sibling with a Developmental Disability," *The University of Mississippi Undergraduate Research Journal*: Vol. 2 , Article 6.

Available at: <https://egrove.olemiss.edu/umurjournal/vol2/iss1/6>

This Article is brought to you for free and open access by eGrove. It has been accepted for inclusion in The University of Mississippi Undergraduate Research Journal by an authorized editor of eGrove. For more information, please contact egrove@olemiss.edu.

The Early Adulthood Experience of Having a Sibling with a Developmental Disability

Erratum

2017-04-01

The Early Adulthood Experience of Having a Sibling with a Developmental Disability

Carole Frances Jennings

Advised by Dr. Robin Wilkerson, Ph.D., RN

Edited by Dr. Gary C. Glick

Abstract

This qualitative study explored the early adult's experience of having a sibling with a developmental disability and influences on the experience. The phenomenological method was used, specifically the approach of hermeneutic phenomenology as discussed by van Manen. The phenomenological investigation included the collection of data from the experiential descriptions of the participants gathered during interviews. Based on reflection on the data, essential themes of the experience and influences on the experience were identified. To describe the situational context of the participant, demographic data were collected. Five essential themes of the early adulthood experience of having a sibling with a developmental disability were identified. (1) There were lessons to be learned from their siblings, and knowledge of the experience of the early adults offered something for others to learn. (2) The experience included contemplations on the future including: financial responsibility for, managing the care of, and living arrangements for their siblings with a developmental disability, and future children. (3) The early adults in this study were pragmatic. (4) The early adults in this study had intimate relationships with their siblings. (5) Protectiveness was expressed by the early adults, which included advocating for their sibling and concern for their sibling. Two influences were common among all early adults in the study. The early adult's perception of their sibling and their situation as normal to them while growing up influenced their experience. Another influence was the parents of the early adult. This included their parents' mindset on, actions towards, and approach to the situation.

I. Introduction

The sibling relationship is different from other familial relationships. The sibling relationship is commonly characterized by a shared cultural background, shared experiences, and typically shared genetics. Factors such as parental absence, work stress, or marital stress may also contribute to the strength of the sibling bond (Goetting, 1986). More specifically what does the sibling relationship look like in early

adulthood? Early adulthood is a period of development characterized by many decisions about education, romantic relationships and spouse seeking, career planning, and even selecting city of residence (Graber & Brooks-Gunn, 1996). Young adults have vast opportunities ahead of them, and in this time they make many decisions regarding their future (Newman & Newman, 2012).

Developmental disabilities are more prevalent in today's society than

ever before. A developmental disability is any of a group of conditions that are due to impairment in physical, learning, language, or behavior aspects of an individual (The Centers for Disease Control and Prevention, 2013). According to the Centers for Disease Control and Prevention (CDC), these conditions start in the developmental period, may impact daily functioning, and persist throughout the individual's lifetime. A study completed for the CDC and the National Center for Health Statistics estimates that one out of six children aged 3-17 years, have one or more developmental disabilities (Boyle et al., 2011). In 2014, there was a 5.76% lifetime prevalence of developmental disabilities in children aged 3-17 as reported by parents in a National Health Interview Survey (Zablotsky, Black, Maenner, Schieve, & Blumberg, 2015). Additionally, the trend in deinstitutionalization is increasing the number of individuals with a developmental disability residing both at home and in the community (Lakin, Larson, Salmi, & Webster, 2010). Further, the life expectancy for individuals with developmental disabilities is now similar to that of the general population unlike in previous decades when individuals with developmental disabilities died at a younger age (Heller, Staffor, Davis, Sedlezky, & Gaylord, 2010). Thus, more people than ever are living through early adulthood as siblings of a person with a developmental disability.

For the context of this study and as developed by the researcher, *early adulthood* is the time period of development between ages 21 and 35 years. Additionally, a *developmental disability* is, according to the Federal Developmental Disabilities Act, a severe and chronic disability experienced by an individual with the following characteristics: mental or physical impairment or a combination of both, is apparent prior to the age of 22, and reflects an individual's need for services and support. A developmental disability causes functional shortcomings in at least three of the following: self-care, language, learning, mobility, self-direction, capacity for independent living, and economic self-sufficiency (Developmental Disabilities Act, 2000).

II. Significance

Many important life decisions are made in the period of early adulthood. Erikson (1963, 1964) believed the developmental stage of early adulthood to be from 20 years old to approximately 40 years old and labeled the developmental task of individuals in this range *Intimacy vs. Isolation*. This intimacy is defined as the ability to devote the self to affiliations and partnerships and then to remain loyal to these commitments even when sacrifice or compromise is required. Without this intimacy, individuals attain a sense of isolation and are reluctant to establish commitments, because these

commitments are seen as a risk to the identity formed in the previous developmental stage (Erikson, 1963, 1964). In a 1993 article, Chickering and Reisser (as cited in Glover, 2000) described seven vectors that together represent the psychosocial and cognitive transitions that occur as individuals enter young adulthood from late adolescence. The seven vectors include intellectual, physical, emotional, moral and interpersonal dimensions, with identity as the central theme. Identity is the individual's acceptance of his or her own characteristics. Chickering and Reisser stated that identity is typically not developed until the late 20s and is never complete.

Considering the few studies related to individuals in early adulthood with a sibling with a developmental disability and the importance and uniqueness of this developmental stage, further research is warranted to increase the existing knowledge from this perspective. Gathering data from the early adult provided perspective into the relationship and experience of having a sibling with a developmental disability. From this study a descriptive theory of the meaning of the experience emerged. Influences on the experience also emerged.

III. Review of Literature

A review of literature revealed few studies that focused on the experience of early adults who have a sibling with a developmental disability.

The literature review includes research related to sibling relationships in early adulthood as well as sibling relationships in adulthood when a sibling has a developmental disability. Only two qualitative studies were found by the researcher on individuals who have a sibling with a developmental disability. The researcher found no qualitative studies specifically on early adults who have a sibling with a developmental disability.

IV. Sibling Relationships in Early Adulthood

Siblings provide the longest-lasting relationships within the family and frequently develop closeness as other family members age and extended family members die (Goetting, 1986; White, 2001). They also have the unique aspect of rivaling for parental affection and attention that is not typical of other familial relationships (Furman, Lanthier, & Stocker, 1997). The researchers used a self-report questionnaire and analyzed reports on three categories of sibling relationships: warmth, conflict, and rivalry. The researchers reported the following correlations: the perception of warmth in the sibling relationship was positively correlated to how often the siblings had contact; the number of siblings (children within the family) was positively correlated with the perception of conflict and rivalry and negatively correlated with the perception of warmth; and people with high scores of psychological functioning

and mental health reported less conflict in their sibling relationships (Furman, Lanthier, & Stocker, 1997).

Research conducted by Conger and Little (2010) focused on how sibling relationships change during early adulthood. Several of the transitions occurring in this developmental period include: pursuing or finishing education, job seeking, establishing romantic relationships, perhaps even marriage, childbearing decisions, and moving away from the natal home. In typical sibling relationships, there is also a certain amount of competition during this period of development. One sibling may feel less adequate based on his or her success in job seeking or job-attaining or in finishing their education when compared to their sibling (Conger & Little, 2010).

A panel analysis conducted by White (2001) used pooled time series techniques on a national panel sampled by the National Survey of Families and Households to investigate sibling relationships of the life course. It was reported that in a typical relationship, communication and closeness between siblings decreases during early adulthood, most likely attributed to one or both siblings leaving home and establishing a family of their own that consumes more of their time (White, 2001). Researchers also reported that across all groups, sisters were the most inclined to maintain and strengthen their sibling relationships (White, 2001).

V. Sibling Relationships in Adulthood with a Sibling with a Developmental Disability

A study conducted by Floyd, Costigan, and Richardson (2016) focused on the progression of the sibling relationship over the life course and sibling relationships in which one sibling had an intellectual disability. Researchers in the study reported that sibling relationships in which one sibling has an intellectual disability, when studied during adolescence and young adulthood, had a strengthening of the emotional bond and a reduction in sibling conflict as the dyad progresses through the development (Floyd, Costigan, & Richardson, 2016).

A study by Heller and Kramer (2009) focused on the sibling involvement in future planning. In their study, they reported that 38% of siblings anticipated becoming the primary caregiver to their sibling with a developmental disability. The mean age of sibling respondents in the study was 37 years old. Several factors influenced this anticipation and included the gender of each sibling, the proximity of the living situation of both siblings, and the amount of contact and support between siblings (Heller & Kramer, 2009).

Two studies compared sibling dyads in which one adult sibling was diagnosed with either autism spectrum disorder or Down syndrome. A study by Orsmond and Seltzer (2007) focused on the adult sibling relationships

occurring when one sibling has either an autism spectrum disorder or Down syndrome. The study included a series of questionnaires involving more than 150 siblings between the ages of 21-56 years. In this study adult siblings of a person with an autism spectrum disorder more often had feelings of pessimism about the sibling's future, less personal contact, and effects reaching outside the sibling relationship occurred (Orsmond & Seltzer, 2007).

The second study was a large web-based study using questionnaires. The study included 460 adult siblings of persons with disabilities: 284 were adult siblings of individuals with Down syndrome, and 176 were adult siblings of individuals with autism. The average age of the adult siblings of individuals with Down syndrome was 36.7 (\pm 13.9), and the average age of the adult siblings of individuals with autism was 30.6 (\pm 12.6) (Hodapp & Urbano, 2007). They found that individuals with an adult sibling with Down syndrome had better health and lower levels of depressive symptoms compared to individuals with adults with Autism spectrum disorder (Hodapp & Urbano, 2007).

A study conducted by Burbidge and Minnes (2014) investigated the similarities and differences of relationship quality of siblings without a developmental disability and that of siblings in which one sibling has a developmental disability. The study was conducted in two parts and used a

questionnaire. A person with one sibling with a developmental disability as well as another sibling without a developmental disability filled out two separate questionnaires about his/her relationships with each of the siblings. Participants rated their closeness to their sibling with a developmental disability as greater than their sibling without a developmental disability, but rated their closeness in behaviors, referring to shared activities, as greater in similarity to their sibling without a developmental disability (Burbidge & Minnes, 2014).

O'Neill and Murray (2016) conducted a study focusing on the prevalence and symptomatology of anxiety and depression in adult siblings of individuals with developmental disabilities including Down syndrome, autism spectrum disorder, Prader-Willi syndrome, and those with a developmental disability of unknown etiology. The study included 132 non-disabled siblings of individuals with the aforementioned disabilities who were 18 years or older and 132 non-disabled control group participants. The mean age for the sibling group was 33.83 (\pm 10.69) and for the control group 37.03 (\pm 12.34). The data were gathered via questionnaires sent to disability charities. The researchers reported that all of the sibling groups who had a sibling with a disability reported elevated levels of anxiety and depression symptoms compared to the control group based on the siblings'

reports of their symptoms (O'Neill & Murray, 2016).

Arnold, Heller, & Kramer (2012) conducted a study regarding the support needs of individuals who have a sibling with a developmental disability. The participants in this study were 18 or older with an average age of 37 years old. The study was conducted using two open-ended questions attached to a questionnaire. The researchers stated, "Numerous respondents shared the importance of targeting siblings as a group with support needs because they have felt neglected and desperately wanted to be included" (Arnold, Heller, & Kramer, 2012, p. 377). Highlighted in the study were participants' sentiments that getting the conversation started about future planning was the biggest step and then worry about what will occur when parents die could be discussed (Arnold, Heller, & Kramer, 2012). The highest ranking need in the study was sibling support services. The participants' inquiries for more education and training opportunities, such as conferences, workshops, and seminars, demonstrates their desire to connect with others in similar situations, share needed information, and aid in supporting one another (Arnold, Heller, & Kramer, 2012).

The early adulthood time period is especially relevant when considering a review of adult sibling literature conducted by Heller & Arnold (2010). The review of literature included 23 studies published between 1970 and

2008 on adult siblings over 21 years of age who had a sibling with a developmental disability. The literature review reported a mixture of positive and negative psychosocial outcomes. The researchers reported eight studies in which researches found positive psychosocial impacts for siblings of adults with a developmental disability, and five studies in which researchers found negative psychosocial impacts for siblings of adults with a developmental disability (Heller & Arnold, 2010). The researchers reported that non-disabled siblings felt knowledgeable about the needs of their sibling with a disability and that the majority of studies reviewed reported that non-disabled siblings had positive relationships with their sibling with a disability (Heller & Arnold, 2010).

In relationship to common developmental tasks relevant to early adulthood, there has been no conclusive research findings regarding the influence of a sibling with an intellectual disability on life course decisions including marriage, career choice, and the decision to have children (Burton & Parks, 1994; Davys, Mitchell, & Haigh, 2016). Several studies specifically researched the effect of having a sibling with a disability on career choice, a choice that is very prominent in early adulthood (Burton & Parks, 1994; Marks, Matson, & Barraza, 2005; Davys, Mitchell, & Haigh, 2016). Burton and Parks (1994) conducted a study with college students and found

that no significant differences in career aspirations existed between individuals with siblings with or without disabilities. In another study conducted by Marks, Matson, & Barraza (2005), the researchers reported that siblings did choose their career path based on their experience with their sibling with a disability; however, their study population consisted entirely of individuals already working in the special education field. These siblings expressed that their experience with their sibling led to an interest in that specific field and instilled in them a desire to help others in similar situations (Marks, Matson, & Barraza, 2005).

Davys, Mitchell, and Haigh (2016) conducted a study using semi-structured interviews with 15 participants aged 30-64 years and reported 9 of 15 participants in adulthood had a degree of engagement with health and social care either by a paying job or volunteer services, which suggested a link between career choice and intellectual disability for some siblings. The results from Davys, Mitchell, and Haigh's study (2016) on the influence of a sibling with an intellectual disability on the decisions in partners and in whether or not to have children were mixed. Two of the 15 participants in the study reported obtaining counseling for mental health needs while in adulthood due to the presence of the sibling with an intellectual disability, thus providing evidence that more sources of

information during early adulthood may be beneficial to this population (Davys, Mitchell, & Haigh, 2016).

There was evidence that the gender of the sibling of the individual with a developmental disability played a role in the sibling relationship quality and experience (Greenberg, Seltzer, Orsmond, & Krauss, 1999; Orsmond & Seltzer, 2000). In the study by Greenberg, Seltzer, Orsmond, and Krauss (1999), sisters provided more emotional care for their siblings than brothers provided for their siblings with either an intellectual disability or mental illness. Similarly, in the study conducted by Orsmond and Seltzer (2000), sister siblings of individuals with mental retardation provided more caregiving, companionship, and positive affect than brothers of individuals with mental retardation (Orsmond & Seltzer, 2000).

VI. Methodology

Phenomenological methodology was used in this qualitative study, specifically the method of hermeneutic phenomenology described by van Manen (1990). Through phenomenology, the researcher described and unfolded the early adulthood experience of having a sibling with a developmental disability. According to van Manen, hermeneutic phenomenology involves six methodological activities: 1) selecting phenomenon which genuinely interests us and commits us to the world, or

turning to the nature of lived experience; 2) exploring experience as we live it rather than how we think about it, or existential investigation; 3) contemplating the themes which characterize the phenomenon, or phenomenological reflection; 4) transcribing the phenomenon in writing, or phenomenological writing; 5) maintaining a strong relation to the phenomenon; and 6) balancing the research context by reflecting on parts and the whole (Polit & Beck, 2010). The intention of this process is to reflect the meaning of the experience in a manner that can be understood by the reader (van Manen, 1990).

VII. Procedure

After the University of Mississippi Institutional Review Board approved the study, experiential descriptions were obtained from the participants via interviews. The researcher recruited participants by announcements in person in classes in the Psychology department or in the Sally McDonnell Barksdale Honors College e-mail newsletter and also through snowball sampling. Qualitative studies do not claim generalization covering a greater population; therefore, if the participants are in fact members of a small group of acquaintances, then the credibility and trustworthiness of the study is not necessarily compromised.

The participants were asked to participate in a singular interview lasting for one to two hours. Interviews took

place in a location of the participant's choosing or by phone. Only the participant and the researcher were present for the interviews. Data collection was conducted in a room in which the confidentiality of the participant's conversation was ensured. The interviews were recorded using the AudioNote application for iPads for later transcription and analysis. The participant was asked to give consent for the recording of their interview to be used and also consent that they were over the age of 21 and agreed to participate in the study. Once consent was obtained and prior to the interview, demographic data was obtained from the participant and also the data about the sibling were collected including: diagnosis as reported by participant and major life activities impacted by the developmental disability as listed in the Federal Developmental Disabilities Act of 2000. The researcher began the interview with the question: "What is your experience in early adulthood of having a sibling with a developmental disability?" All other questions evolved as the interview proceeded. Each interview was transcribed verbatim and verified for accuracy.

Each participant was assigned a unique participant number, and only the participant number was attached to the data to protect the confidentiality of the participants. Participants were also assigned a pseudonym. A chart connecting participant name, pseudonym, and participant number

was kept safely. All data were kept in a locked file. Consent forms and the chart containing participant name, pseudonym, and participant number were kept in a separate locked file.

VIII. Participants

There were six participants in the study. There were no exclusions related to race or gender. Participants in the research study met the following criteria: (1) were between the ages of 21 and 35 years old, (2) had a sibling with a diagnosed developmental disability according to the guidelines set by the Federal Developmental Disabilities Act (2000), per self-report, (3) were able to communicate efficiently in the English language, (4) were able to hear (with or without assistive devices). It was assumed that the participants were accurately aware of the diagnosis of their sibling(s). Demographic data for the participants were collected including: age, gender, ethnicity, city of permanent residence, education, total number of siblings with/without a developmental disability, and total number of years lived in same household as sibling. The participants included persons aged 22 years to 28 years. Three participants were female, and three participants were male. Four participants had earned a bachelor's degree. One participant had earned a master's degree. One participant had completed some college. Five participants were White, and one participant was multiracial.

IX. Analysis

Certain experiential themes were common or possibly common among all participants; therefore, these themes were compared across interview transcripts to look for similarities and differences. The researcher then selected which themes, common among participants, emerged as representing the meaning of the phenomenon of the early adulthood experience of having a sibling with a developmental disability. To increase credibility and dependability, the adviser of the researcher analyzed the data for individual and common themes separately from the researcher, and later the adviser and researcher together discussed and selected the individual and common themes. Following the conclusion of reflective analysis and definition of essential themes, phenomenological writing began. After completion of phenomenological writing, the phenomenological nod was used to establish credibility of the writing. The phenomenological nod is the agreement of others reading or hearing the phenomenological writing of the investigation (Munhall, 1994). For the purpose of methodological rigor the phenomenological nod needed to be obtained from the participants, because they are the only ones who could answer the question of whether the writing reflected what the experience was like for them. All participants

contacted concurred with the findings of the study.

X. Findings

The purpose of this study was to describe the early adulthood experience of having a sibling with a developmental disability. In this chapter, the essential themes and influences on the participants' experiences are described. The findings are presented in terms of themes and will be illustrated by quotes written in italics. Five essential themes and eight variations were identified (Table 1). The variations display how the themes presented differently among the participants. Two influences on the early adult experience of having a sibling with a developmental disability are also discussed.

Table 1. Essential Themes of the Experience and Their Variations

THEMES	VARIATIONS
1. Lessons learned	a. A lesson to learn from my sibling b. Something for others to learn from my experience
2. Protective	a. Advocating b. Concern
3. The Future	a. Children b. Financial responsibility c. Living Arrangements d. Managing care

4. Intimate with Sibling	
5. Pragmatism	

XI. Essential Themes with Variations

1. Lessons learned.

Each participant expressed that their experience offered lessons to learn. The two variations on this theme were: that there was a lesson to be learned from their sibling and that others had something to learn from their experience. Participants spoke of their siblings with gratitude for the lessons that their experience has afforded them. Some participants expressed that there is something for them to continuously learn from their sibling. One participant thought that her sibling was able to teach her a lesson through her sibling's perspective on life and even believed that her sibling served as a role model in her life.

"Because she is in a way my role model for life with the way she is into her things, her perspective on life, and the purity of her heart kind of thing."

Some participants expressed that they are the person they are because of their sibling. Some participants thought that their sibling had taught them a specifically valuable life lesson. They shared that their own personalities and perspectives had been altered by their experience with a sibling with a developmental disability.

"I know for a fact that if she was not my sister that I'm pretty sure I would be a lot more selfish. I guess I would take a lot of stuff for granted honestly. I know I would. I mean I'm not proud of that at all. I just don't feel like- it's been a lot easier as a teaching lesson for her to be my sister to learn: don't take stuff for granted.

So I definitely had to learn a lot of patience, kind of adaptability to that situation. You know, I didn't know anybody that had a sibling with Down syndrome. I didn't know anybody with Down syndrome, except him... So it was kind of a learning curve, adapting to that situation, and kind of having to understand that most things aren't going to come easy. It's going to take a lot more time and patience and a lot more work for him to accomplish the things that somebody his age normally would. That's pretty much how it always was. It was just kind of having to learn to slow down. The patience was the biggest virtue, or attribute, that I had to learn.

[My brother] is a huge part of who I am, and he is my normal in that he is one of the things that has made me who I am. He's probably one of the biggest, or the biggest that has made me who I am. And I really like who I am right now... I don't think I would change it. I don't know. If [my brother] was different, then I would be different... We are definitely related. Well at least he is the cause and I'm the effect. So whatever he would have been like,

ultimately I think I would have ended up being like. So certain qualities that I really value in myself, like being able to take care of people, being passionate about things, being confident, or being vulnerable, and being sensitive, extra-sensitive to people, and being so aware, socially aware of what's going on around me. All these different qualities that I really value and that make me "me" are directly related to [my brother] and my relationship with him. Being able to be mature at a very young age was something that everyone always pointed out in me, and I know that is something that I know is due to [my brother]."

Some participants expressed that others have something to learn from their experience. Participants thought that if other individuals without siblings with a developmental disability were exposed to their experiences, other individuals would also learn valuable life lessons.

"I do think we all could learn something by living a day or two with somebody with a disability and seeing how life is with that and really just kind of seeing for the most part, like yourself, that might not have a sibling with a disability to understand and see just how life- you don't know how that life is until you're put into a position to where you know somebody else is dependent on you no matter what. And I'm not saying it's a bad thing. It's not, but it's

just more- I consider it knowledge. You know, its more knowledge for somebody to have to understand what it's like to have to go through life like that."

2. Protective.

Each participant displayed protectiveness over his or her sibling. Participants demonstrated their protectiveness in two different ways: by expressing concern and by advocating for their sibling. Participants expressed concern regarding their sibling's safety and well being. One participant expressed concern regarding her sibling's safety as she and her family encouraged more independence. Another participant expressed concern about his/her sibling being able to handle being in the real world without his/her help. Another participant similarly expressed concern about his/her sibling living in a group home or anywhere where they were not able to care for his/her sibling.

The goal is for her independence to grow, but at the same time one of the biggest fears is her being taken advantage of. Obviously it happens to females, but can happen to males. I worked in adult programs, and I've heard horrific stories, just horrific stories.

"I think I'm protective, like possessive of him [brother] as well. And just the idea of me being so far and not having a say over anything in his life

made me uncomfortable, and I think that's something that I'm really figuring out right now and deciding having to do day-by-day and also trying to think ahead so that I'll be prepared. That's hard to do, because you just don't really know what's going to happen.

It's hard, because I see him- suffering is a harsh word- but suffering down here with no friends, still living with mom and dad, and here I am trying to put my life together. At the same time I want to help him put his life together too. I feel like he counts on me for things that are out of my control."

Participants advocated on behalf of their sibling, which was interpreted as a variation of protectiveness.

Participants expressed that their sibling should not be messed with and by expressing that their sibling should not be underestimated. Some participants expressed that their sibling should not be messed with by standing up for them in some capacity. One participant demonstrated this variation of protectiveness as he tried to stop a bully from picking on his sibling. Some participants felt that other peoples' use of the "r-word" was offensive to them and their sibling, so they stood up for their sibling by promoting the disuse of the word.

"So on Friday night football games my sister would come, and there would be some people, not all... I use the term "ignorance", not in a negative way, just they truly did not know,

because they weren't around it. So that kind of was something that I struggled with, and I was very vocal, even later in college, you know if people used the "r-word" even just for joking. If they said "Oh that's so retarded." I would immediately say, "Please don't use that word around me." I would be very quick, and you know people would always feel bad. But that's a precedence I set early on."

Participants expressed that their siblings should not be underestimated. One participant advocated for his sibling as he tried to facilitate social situations in which his sibling was involved. He sat down and talked with his friends and also his sibling before his sibling came to stay with him in college. He wanted everyone involved in the social situation to be prepared for the encounter in order to protect his sibling. Participants thought that others underestimated the intelligence and the abilities of their siblings. They defended the intelligence of their siblings despite the fact that they were aware that their sibling had a developmental disability. They also believed that underestimating their siblings was not helping them reach their full potential and full range of capabilities.

"She has a lot more cognitive ability than a lot of teachers thought that she had, and my mom knew that and she was mad that they weren't trying. They were teaching her how to wash dishes, stuff like that, and it's like

okay she knows how to memorize some Spanish. She knows Spanish pretty darn well, which is crazy. She can do simple math, but she has a hard time writing. Anything you try to teach her with complex ideas or discussion, she doesn't follow. She knows very basic stuff, like in the math area or Spanish-different areas that you wouldn't think they get or understand she does really well in.

I don't let a lot of my friends kind of baby her, or be easy with her, because I know they're not here 24/7. I know that she can do this stuff.

He does make eye contact with you. He's not like not present. I really do believe that something is, you know, he knows more than you think. Just because he can't communicate it with you- there's like little things. You know, I'll talk to him and tell him to close the door of the car, and he closes it. He like takes some time, but he'll do it himself. I'll talk to him. He knows the way home. It's really funny on the way home, if you take this right instead of a left to go to like Starbucks or Publix to get something, and he'll scream in the car and freak out. All I have to do is tell him where I'm going and why I'm going there, and it's really funny."

3. The Future

Each of the participants discussed their contemplations on the future. There were four variations regarding thoughts on the future: financial responsibility for their sibling;

future living arrangements for their sibling; managing the future care of their sibling; having children. Participants said that they intended to become financially responsible for their siblings in the future and had already made some efforts towards that goal.

"So if something were to happen to my parents, let's say there are three of us siblings so technically a family would divide things three ways in their will. Well if anything is left under her [sister with developmental disability] name, then she will not qualify for services, and she will be kicked out of services. There is something going through legislation now called the Able Act that has been passed and looks to help in that area. I am the executor of the special needs will and trust, so it is basically money allocated to her but not under her name. I am also the guardian or conservatorship, if something were to happen to my parents."

Participants discussed the possible future living arrangements for their siblings. Some participants intended for their sibling to co-reside with them. Some participants intended for their siblings to live in their own space but very close by. One participant thought that his sibling would live with one of his aunts in the future.

"I've mentioned it to my brother, and he's said she is welcome to stay

there or it depends on the situation, if she stayed with us for a year or two and then went over there for a year or two. He seemed okay with it, so if something ever happened she was with one of us. That's the most extent that we've talked about it, but I guess when that bridge comes we'll have to make a decision.

Yeah, I mean my plan, and it has been for a while, is to hopefully, eventually by the time I'm 30 or so to be in a position, you know financially stable enough and things like that, to be his primary caretaker. The goal is to buy a house with like an apartment over the garage, or maybe buy two houses one a lot smaller, just so he can have his own place and take care of himself and live as independently as he possibly can, while I can still be nearby as a support system.

And I don't think my mom wants necessarily to put that burden on me. I don't want to say it's a burden, but you know I don't think she wants to kind of... You know, she understands that I'm young and still growing... And so you know, it's something we'll have to talk about in the near future, but that's not something that we have talked about. I think we've mentioned it once or twice, and it kind of gets blown off to the side. But for the most part, I will say that I will definitely not be alone if something was to happen."

One participant discussed the intention to have children. She reported that she had already sought the advice

of a doctor on whether or not she was at a higher risk for having a child with a developmental disability because of her sibling.

"When I want kids, not any time soon, but when I do that will be in the back of my mind. Nothing is genetic. I've talked to the doctor about it, because I wasn't really sure... I was wanting to know if complications of pregnancy were genetic or if I was having any risk factor of having it, but he said no."

Participants discussed the intention to manage care for their sibling. Each intended to participate in the caring for their sibling in some capacity. Some participants reported that their sibling and their care needs influenced their job choice.

"My priority is feeling comfortable in making the next steps that I can make to support him [brother]. So yeah, I'm going to take a better paying job over maybe a cool unique job traveling around Europe. I'm going to take the higher paying job that's in America, because its closer to my family and its more financially sound, and it can help me almost, if anything, have a higher and higher salary. I feel almost guilty for thinking that way and thinking that you know I want to get a job that pays a lot. I hated that idea. I'm the most "Follow your passions. Do what you love. Like live

through your experiences" type of person, but I also realize like what is my passion? And my passion is my brother and making sure that he's okay always.

I guess I don't have like an open field of options. I have that for a limited amount of time. I think something that is kind of unsettling to me is that I know that eventually I will have to make decisions based off my ability to take care of [my brother]. I think a lot of my decisions now are definitely motivated by: Is this going to help you take care of [your brother]?

It's in the back of my mind that if I had to, I still need to be able to provide for him if I had to, or help him... but that doesn't mean I have to necessarily pick a particular career. I can do whatever I want to do. I just kind of have to keep that in the back of my mind that I'm going to have to be responsible for him at some point in his life."

4. Intimate with sibling

Each of the participants reported an intimate relationship with their sibling. The participants spoke of their sibling fondly and with affection. The participants also talked to their sibling frequently and reported a close bond with their sibling, despite varying physical distances between them. One participant lived in the same household as her sibling and was in contact with her sibling daily. Some participants lived in the same city as their siblings and saw their siblings more than once a

week. Some participants lived in separated cities (4 hours or less away) from their siblings but saw them frequently. One participant lived in a separate city (9 hours away) from his sibling and saw his sibling occasionally. The siblings of four participants had cell phones and frequently used them to contact the participants. Two participants illustrated their close relationship with their sibling by describing their continuing communication after they moved away for college or work.

"It was tough at first. He called me a lot. He has a cell phone, which by the way he can operate masterfully. He called me a lot, like every single day. It took him a while to really kind of grasp what I was doing there, why I left, why I wasn't coming home every day. Then it just became that he wanted to do it too. He's always looked up to me and always kind of wanted to do what I'm doing. Then he got it in his mind like, "Well I want to move out and go to college too." The hardest part was him understanding what I was doing and why I was there.

He texts me more than he texts anyone else by far, I guarantee you. Really in the last year and a half, I bet he texts me 15-20 times a day."

The participants described having relationships with their siblings that were intimate and strong enough to overcome obstacles that they faced.

They elaborated on the difficulties of maintaining a close sibling bond while also knowing they are in a caretaking position for their sibling as well. They discussed the effort required to preserve their close relationship even through physical separation as early adulthood has brought them out of their natal home. The participants seemed eager and willing to make the efforts necessary to help their sibling feel loved and befriended, and the participants also seemed to genuinely have a friend in their sibling.

"She gets a little headstrong. I think we both do, because it is hard because in a way first and foremost we are sisters but at the same time I'm caretaker-ish. I'm very momma-bear, even though she already has a momma-bear.

But it's another thing having to explain why I'm so far away and why I don't get to see him as much. The thing is now he's 20 years old, so he tends to understand real world concepts a lot better. So he understands that I'm out here working and the reasons, but it's definitely even harder than when I went to college just because, like I said, I'm his primary person that if he has something he wants to tell somebody, he wants to tell it to me. We're both kind of having to adjust to being able to do that on the phone a little bit better."

5. Pragmatism

Pragmatism was a characteristic

of participants in this study. The participants realized the good and the bad in life were unavoidable, and they made their best efforts to accept the events of life as they came. They were accepting of their situation and the differences their situation had from those of others. One way that pragmatism manifested was in accommodations made by participants in order to fit their siblings' needs. They described these accommodations as a necessity more than a choice.

"But there are just certain things we couldn't do or had to do in a different way. You know, going out to dinner, we would go early. We would always be the early birds, with the people who were older for the early bird special, because putting your name in and having to wait, and those kinds of things. Going to stores, having to be in line, we would tag team and have someone walk around the store with her while someone else waited in line.

It was always a coordination of who's home. Like, Regan you need to go home. Like today, I'm picking up [my brother] from his day center because my mom works until four, and when I'm here it's a great help because we don't have to pay someone else to pick him up and take him and sometimes she's not available. It's always asking when and who is going to be home and you can't leave without someone knowing, because someone has to be here with [my brother] or you have to take him

with you. Then it's: can you take him with you? Everything we do is always a question of like who is going to watch [my brother] or can we take him or how is this going to work? For example, for my graduation: I wanted him there for my high school graduation and we had to take a babysitter just in case he made noise to take him out in the back, and like it was this whole operation just to have my brother at my graduation.

I already know in my mind if the same situation- some people might see her as- I guess like an obstacle, makes life harder. And I'm not saying that she doesn't make life harder. I mean you have to set a little more time to make two people like more, make sure that she's fine. You can't always get up and go to the grocery store, if you're the only one at the house. You know to stay there. Burden! Some people think she's a burden. That's the word! I feel like what's the difference in just having a younger child? Anybody can view them as a burden interrupting conversations or anything. It's just like taking care of a younger child, but forever."

One participant expressed pragmatism by discussing the fact that his situation could actually be worse. He explained his sibling's disability and symptoms and then explained that other persons with the same disability have more severe symptoms than his sibling.

"I will say for her personally,

there are a lot of Angels [persons with Angelman syndrome] that we know about and are confined to a wheel chair. And she is not, so we feel very fortunate that she can walk on her own, because having someone in a wheelchair on top of not being able to talk and not being able to kind of explain yourself is you know, it just makes things harder. There's really no nice way of putting it, but it's just not great for anybody. We are definitely fortunate that she can walk on her own and get around on her own."

Another participant expressed pragmatism by discussing how their family's accommodations were actually not helping his sibling. He expressed that realistically his sibling could achieve more if the family pushed the sibling to do more things instead of catering to the things that the sibling cannot do. The participant was not oblivious to the manifestations of the sibling's disability, but simply felt that accommodating was keeping the sibling from reaching their full potential.

"I guess when you have a kid, or a brother, with a disability you really want to treat them the same as if they didn't have it you know, like there was no disability, especially with [my brother]. For [my brother] when you're trying to get to the point where he can be independent and live by himself, you have to treat him like a normal person without a disability. Every time you treat

him like he has a disability, it cripples him."

6. Influences on the Experience

The participants described two influences on their early adulthood experience of having a sibling with a developmental disability: their parents and their perception that their experience was normal. These influences emerged from the participant interviews when asked to describe the experiences of having a sibling with a developmental disability. A discussion of these influences follows. Influences are illustrated by quotes written in italics.

Parents

The participants described how influential their parents were on their experience. They identified how their parents facilitated their relationship with their sibling, helped explain to them their sibling's disability, and modeled the accommodations in their daily life in order to help the sibling with a developmental disability. Participants discussed the lessons that they have learned from their parents through the experience. The parents' approaches to the situation influenced the participants. Participants evidenced that even in situations where parents are not still married and co-residing, the parents had influence on their experience.

"Like I'd be walking through the hallways, and he'd be in the classroom

with just the teacher. And that's when I kind of figured it out, and I asked my mom. And she said, "Nothing is wrong with him. He's just... underdeveloped. His brain is underdeveloped. You know, he's older than you, but... he's 12 years old, but he may have the mind capability of a 6 year old or 7 year old."

I think my parents have done an amazing job always being advocates for her, and that's what has gotten me into the field. I think the reason she has progressed as much as she has is because we do know her rights. My parents have always killed with kindness... They were always well educated and worked together. I do see an impact that it had on my parents' marriage. I do think that that's something just like with any children. But their faith was a firm foundation, which taught me a lot of things now that I'm married, you know, how to approach relationships. I generalize what they went through and how they dealt with things, and I think it's a testimony to their faith.

Like my mom, you're not always going to have the best outcome. Don't expect or assume everything is going to be okay. Always be prepared for the worst, even if it comes out the best. Always be prepared for the worst.

Our parents got divorced when we were younger, so that definitely drew us a lot closer. We've split time between our parents, like one week with mom and one week with dad, back and forth like that, but since me and

him were always doing it together, I think that's what kind of established our bond so strongly because we were kind of in that together."

Normal to me

Participants related that their perception that their life and their sibling were normal had influenced their early adulthood experience of having a sibling with a developmental disability. They had always known their sibling with a developmental disability and would never know their sibling without their developmental disability. They acknowledged that over time they realized other families were different than their families. While some participants discussed coming to an understanding, they did not remember ever being unaware of their situation. They described the perception of their sibling and their situation being their version of normal. The majority of descriptions were of situations in childhood or adolescence; however, it appeared that this greatly influenced the participants' early adulthood experiences.

"... I never looked down upon her. It was just- I don't know how to explain it- like I guess I just felt like it was normal, you know. I didn't think that- I mean, I know that other kids didn't have siblings that had cognitive disabilities, but for us it was normal. So I didn't think anything was abnormal about it.

I knew that he had- that he was

different, but it was also very confusing, I think to me, because he was my brother and I recognized that it was normal to my family, but then I also started recognizing that it was different to others.

I guess in the beginning for me it was just a normal brother. I don't really know. I mean I knew at a young age that something was wrong with him, but I didn't pay attention to it, you know, because at that age, we did everything together you know... We would do everything that normal brothers would do."

XII. Discussion

Limitations to Transferability

The purpose of this study was not to empirically generalize the findings. The purpose of this study was to attain a better understanding of the early adulthood experience of having a sibling with a developmental disability. The researcher cannot specify the transferability of the findings. The experiences of the early adults in this study might not reflect the experiences of all early adults who have a sibling with a developmental disability.

Implications

The findings of this study represent new knowledge discovered through descriptions of the participants' accounts of their experiences. The essential themes and influences that were identified add to the existing

knowledge, not only to assist with understanding the experience, but also to clarify issues that have been discovered by previous research and that have been described in the literature review. In this section, implications related to practice, education, and research will be explored.

Practice

Some of the themes and influences found in this study pose relevant possibilities for interventions in practice. Firstly, participants believed that there were lessons to be learned from their sibling and their experience with their sibling. Participants expressed that they had learned something worth sharing with others and that others had something to gain from knowledge about their experience. One participant expressed that he felt that his experiences was something that "is overlooked in a lot of people's minds". In practice, early adults may feel more supported and more understood by other individuals, including those without siblings with a developmental disability, if other individuals were more knowledgeable about the experience.

Secondly, participants expressed protectiveness over their sibling. Some participants expressed concern for the mental and emotional health of their sibling when participants left for college or work and left their sibling in an empty nest. It could be beneficial for

early adults to have access to information on how to best prepare their siblings for the transition as well and information on how to best make the actual transition. The majority of participants advocated on behalf of their sibling in situations where they felt someone was messing with their sibling or underestimating their sibling's abilities. Participants advocated for their sibling in social situations with persons without disabilities, when others around them used the "r-word", and when others were bullying their sibling. In practice, if more people had knowledge of the practices that offend or upset siblings of individuals with disabilities, less stress would be placed on the siblings to stand up for their brother or sister with a developmental disability. Also, it could be beneficial for professionals who interact with early adults to understand the protectiveness they feel towards their sibling so that they could help them advocate for their sibling. Professionals could better advise them on how to best advocate for their sibling.

Thirdly, participants heavily discussed their thoughts about the future of their siblings. It was reiterated by all participants that they had not been able to create an exhaustive plan for the future and discuss it with their parents. One participant admitted to being scared to initiate the conversation about the future with her parents for fear that she would upset her parents. In practice, it could be beneficial for the

parents of the early adults to initiate the conversation regarding the future. Participants expressed that not all parts of the plan could be developed because they just did not know what would happen in life before they needed to take over caring for their sibling, but it was common among all participants that they had thought about some aspects of their plan for the future. For one participant, her plan actually was contrary to the plan her parents desired. In practice, it could be beneficial in easing the stress of the early adult sibling for parents to discuss with them their plans and desires for the future care of the sibling with a developmental disability and to ask for the early adult's input in the plan.

Two influences on the early adulthood experience of having a sibling with a developmental disability emerged as common to all participants. Participants thought that their parents had helped to facilitate their relationship with their sibling, helped them to understand their sibling's disability, and modeled the accommodations that their family made for their sibling. It is possible that parents were such a strong influence in their lives, because in a sibling relationship in which one sibling has a developmental disability, parents are needed to provide a bridge between the siblings. Parents may be needed in order for the non-disabled sibling to navigate his/her relationship with the sibling with a disability. In practice, it

could be beneficial for parents to be cognizant of their role as a mediator between the siblings so that they may best facilitate the relationship.

Education

While remaining aware that each early adult's experience is unique, these findings can provide a base for conversations with early adults regarding their experiences. It could be helpful for both the early adult who has a sibling with a developmental disability and their family, if parents and other family members were educated on the essential themes and influences on the experience identified in this study. Knowledge of the findings of this study could assist parents in better understanding more about the experience of their own early adult who has a sibling with a developmental disability. Education of the parents could also assist them in initiating conversations with the early adult regarding his/her experience and how the parents can help them in the experience.

Research

Replication of this study with samples in setting other than the southern region of the United States with a wider range of ethnic and socioeconomic groups would serve to broaden the existing understanding of the early adults' experience. Longitudinal studies of individuals who have siblings with a developmental disability may provide useful

information about differences and similarities of the experience of having a sibling with a developmental disability throughout various developmental stages and, therefore, potentially further increase the knowledge related to the experience of having a sibling with a developmental disability. Additionally, a replication of the study with equivalent or greater heterogeneity in diagnoses of the sibling with the developmental disability and increased participants with siblings with a developmental disability in each homogeneous category of diagnosis would be beneficial in gaining knowledge on differences in the early adulthood experience. This would help elucidate the similarities and differences of early adults' experience across various siblings' developmental disability diagnoses and would provide useful information regarding the experience of early adults with siblings with one diagnosis compared to the experience of early adults with siblings with another diagnosis.

References

- Arnold, C. K., Heller, T., & Kramer, J. (2012). Support needs of siblings of people with developmental disabilities. *Intellectual and Developmental Disabilities, 50*, 373-382.
- Boyle, C.A., Boulet, S., Schieve, L., Cohen, R.A., Blumberg, S.J., Yeargin-Allsopp, M., Visser, S., Kogan, M.D. (2011). Trends in

- the prevalence of developmental disabilities in US children, 1997–2008. *Pediatrics*, 27, 1034-1042.
- Burbidge, J., & Minnes, P. (2014). Relationship quality in adult siblings with and without developmental disabilities. *Family Relations*, 63(1), 148-162. doi: 10.1111/fare.12047
- Burton, S. L., & Parks, A. L. (1994). Self-esteem, locus of control, and career aspirations of college-age siblings of individuals with disabilities. *Social Work Research*, 18, 178-185.
- Conger, K. J., & Little, W. M. (2010). Sibling relationships during the transition to adulthood. *Child Development Perspectives*, 4(2), 87. doi:10.1111/j.1750-8606.2010.00123.x
- Davys, D., Mitchell, D., & Haigh, C. (2016). Adult siblings consider the future: Emergent themes. *Journal of Applied Research In Intellectual Disabilities*, 29, 220-230.
- Developmental Disabilities Act. (2000). *Developmental disabilities assistance and bill of rights act of 2000* (Public Law 106-402, 106th Congress). Retrieved from: <http://www.gpo.gov/fdsys/pkg/P-LAW-106publ402/pdf/PLAW-106publ402.pdf>
- Erikson, E. (1963). *Childhood and society*. New York: Norton.
- Erikson, E. (1964). *Insight and responsibility*. New York: Norton.
- Floyd, F. J., Costigan, C. L., Richardson, S. S. (2016). Sibling relationships in adolescence and early adulthood with people who have intellectual disability. *American Journal on Intellectual and Developmental Disabilities*, 121, 383-397. doi: 10.1352/1944-7558-121.5.383
- Furman, W., Lanthier, R.P., & Stocker, C.M. (1997). Sibling relationships in early adulthood. *Journal of Family Psychology*, 11, 210-221. doi: 10.1037//0893-3200.11.2.210
- Glover, R. (2000) Developmental tasks of adulthood: Implications for counseling community college students. *Community College Journal of Research and Practice*, 24, 505-514. doi: 10.1080/106689200050137273
- Goetting, A. (1986). The developmental tasks of siblingship over the life cycle. *Journal of Marriage and Family*, 48, 703-714.
- Graber, J. A., & Brooks-Gunn, J. (1996). Expectations for and precursors to leaving home in young women. *New Directions for Child Development*, 71, 21.
- Greenberg, J. S., Seltzer, M. M., Orsmond, G. I., & Krauss, M. W. (1999). Siblings of adults with mental illness or mental retardation: Current involvement and expectation of future caregiving. *Psychiatric Services (Washington, D.C.)*, 50, 1214.

- Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of Policy and Practice in Intellectual Disabilities, 7*, 16-25. doi:10.1111/j.1741-1130.2010.00243.x
- Heller, T., & Kramer, J. (2009). Involvement of adult siblings of persons with developmental disabilities in future planning. *American Association on Intellectual and Developmental Disabilities, 47*, 208-219.
- Heller, R., Stafford, P., Davis, L.A., Sedlezky, L., & Gaylord, V. (Eds.). (Winter 2010). *Impact: Feature on Aging and People with Intellectual and Developmental Disabilities, 23*(1). Retrieved from <http://ici.umn.edu/products/impact/231>
- Hodapp, R. M., & Urbano, R. C. (2007). Adult siblings of individuals with Down syndrome versus with autism: Findings from a large-scale US survey. *Journal of Intellectual Disability Research, 51*, 1018-1029. doi:10.1111/j.1365-2788.2007.00994.x
- Lakin, K. C., Larson, S., Salmi, P., & Webster, A. (2010). Residential services for persons with developmental disabilities: Status and trends through 2009. Minneapolis, MN: University of Minnesota, Institute on Community Integration, Research and Training Center on Community Living.
- Marks, S. U., Matson, A., & Barraza, L. (2005). The impact of siblings with disabilities on their brothers and sisters pursuing a career in special education. *Research & Practice for Persons With Severe Disabilities, 30*, 205-218.
- Munhall, P. (1994). *Revisions phenomenology*. New York: National League for Nursing.
- Newman, B. M., & Newman, P. R. (2012). *Development through life: A psychosocial approach*. Belmont, CA: Wadsworth/Cengage Learning.
- O'Neill, L. P., & Murray, L. E. (2016). Anxiety and depression symptomatology in adult siblings of individuals with different developmental disability diagnoses. *Research in Developmental Disabilities, 51*, 116-125. doi:10.1016/j.ridd.2015.12.017
- Orsmond, G. I., & Seltzer, M. M. (2000). Brothers and sisters of adults with mental retardation: Gendered nature of the sibling relationship. *American Journal on Mental Retardation, 105*, 486-508.
- Orsmond, G. I., & Seltzer, M. M. (2007). Siblings of individuals with autism

- or Down syndrome: Effects on adult lives. *Journal of Intellectual Disability Research*, 51, 682-696. doi:10.1111/j.1365-2788.2007.00954.x.
- Polit, D. F., & Beck, C. T. (2010). *Essentials of Nursing Research: Appraising Evidence for Nursing Practice* (7th ed). Philadelphia: Wolters Kluwer Health /Lippincott Williams & Wilkins.
- Seltzer, M. M., Orsmond, G. I., & Esbensen, A. J. (2009). Siblings of individuals with an autism spectrum disorder: Sibling relationships and wellbeing in adolescence and adulthood. *Autism : The International Journal of Research and Practice*, 13(1), 59–80. <http://doi.org/10.1177/1362361308097119>
- Smith, L. O., Elder, J. H., Storch, E. A., & Rowe, M. A. (2015). Predictors of sense of coherence in typically developing adolescent siblings of individuals with autism spectrum disorder: Siblings of individuals with autism. *Journal of Intellectual Disability Research*, 59, 26-38. doi:10.1111/jir.12124
- The Centers for Disease Control and Prevention. (2013). *Facts about developmental disabilities*. Retrieved from: <http://www.cdc.gov/ncbddd/developmentaldisabilities/facts.html>
- van Manen, Max. (1990). *Researching lived experience: Human science for an action sensitive pedagogy*. Ontario, Canada: State University of New York.
- White, L. (2001). Sibling relationships over the life course: A panel analysis. *Journal of Marriage and the Family*, 63, 555-568. doi: 10.1111/j.1741-3737.2001.00555.x
- Zablotsky, B., Black, L.I., Maenner, M.J., Schieve, L.A., Blumberg, S.J. (2015). Estimated prevalence of autism and other developmental disabilities following questionnaire changes in the 2014 national health interview survey. *National Health Statistics*